

New Jersey Department of Health Governor's Council for Medical Research and Treatment of Autism Meeting Minutes – April 3, 2017 (ratified)

Council Members Present

Michael Aquino, MD, F.A.C.G., Senate President Appointee; Partner, Shore Gastroenterology Associates, Cofounder, VP of Operations, Pathology Solutions

Elizabeth K. Bell, BS, Public Member - Individual or Family Member with Autism Representative; Volunteer and Independent Contractor with Autism Speaks

Cheryl F. Dreyfus, Ph.D., Academic Institution Representative; Professor and Chair, Department of Neuroscience and Cell Biology, Rutgers University, Robert Wood Johnson Medical School

*Caroline Eggerding, MD, Healthcare Organization Representative; Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital

Susan P. Evans, Ed.D., Commissioner of Health Appointee; Education Program Specialist for Early Intervention Program, NJ Department of Health

Wilma Judith Friedman, Ph.D., Academic Institution Representative; Professor, Department of Biological Sciences, Rutgers University

Thomas V. Macchiaverna, MA, Public Member Representative; Special Education Teacher Samuel Sheng-Hung Wang, Ph.D., Academic Institution Representative; Professor, Department of Molecular Biology and Princeton Neuroscience Institute, Princeton University

Gary Weitzen, BA, Autism Organization Representative; Executive Director of POAC (Parents of Autistic Children)

*Denotes Council Chairperson

Absent

B. Madeleine Goldfarb, MA, Autism Organization Representative; Founder/Director of the Noah's Ark Institute, via teleconference

Ketan Kansagra, MD, FAAP, Academic Institution Representative; Division of Neonatal Medicine, Children's Hospital of New Jersey at Newark Beth Israel Medical Center

Dana E. Spett, MSW, Autism Organization Representative; Founder/Executive Director, Pony Power Therapies

NJ Department of Health (DOH) Attendees

Martin T. Zanna MD, MPH, Acting Executive Director Governor's Council for Medical Research and Treatment of Autism

Linda N. Boclair, M.Ed., MBA, Executive Assistant Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2 Governor's Council for Medical Research and Treatment of Autism Commission on Brain Injury Research and Commission on Spinal Cord Research

Daphne Robinson, Ph.D., Consultant Scientific Planning Consulting

Public Attendees

Abigail Anker, The College of New Jersey
Eileen McKeating, Ph.D., Research Associate, NJ ACE Coordinating Center
Karen Hood-Kasim MPH, Project Coordinator, NJ ACE Coordinating Center
Anna Dulencin, Ph.D., Consultant, NJ ACE Coordinating Center
Jill Harris, Ph.D., Children's Specialized Hospital
Rich Dreyfus

Note: Motions are numbered.

<u>I. Welcome</u> - Council Chairperson, Dr. Caroline Eggerding called the meeting to order at 6:00 PM and welcomed everyone. She noted with regret Ms. Bell (Liz) would be leaving the Council shortly given her family's move to Colorado within the next few months. Ms. Bell has served on the Council since 2008 first as a representative of Autism Speaks and most recently as a public member with a family member with autism. Her contributions to Council both in terms of her personal experiences and knowledge of autism research have been invaluable. On behalf of the Council Dr. Eggerding thanked Ms. Bell for her years of service and wished her well.

<u>II. Public Meetings Act Announcement</u>- Dr. Eggerding read the Public Meetings Act, followed by roll call.

III. Approval of the December 5, 2016 Council Meeting Minutes

Dr. Eggerding called for a motion to approve the minutes. MOTION by Dr. Dreyfus to approve the minutes was seconded by Dr. Friedman.

1. MOTION to approve the December 5, 2016 Council Meeting Minutes was passed with five members in favor and three members abstaining. One member was absent during the vote, joining the meeting later.

IV. NJ ACE 2017 Grant Applications

Thirty-three grant applications were submitted for consideration for funding by the Council. Applications were assigned to review panels based on content: (1) Clinical Research Pilot Grant Applications (2) Basic Science Research Pilot Grant Applications and (3) Autism Medical Homes Pilot Grant Applications.

Basic Science Research Grant Applications

CAUT17BSP011

Developmental Dysregulation of Inhibitory Neuron Migration as an Experimental Model to Analyze Mechanisms of Pediatric Autism-Epilepsy Syndromes

Dr. Eggerding called for a motion. Mr. Weitzen moved and seconded by Ms. Bell to accept the recommendation to fund CAUT17BSP011.

2. Following a brief discussion, the MOTION to approve the recommendation to fund CAUT17BSP011 was passed with seven members in favor and two abstaining.

CAUT17BSP022

A Role for Semaphorin Functions In Cortico-Basal Ganglia Development, Repetitive Behavior, And Autism Spectrum Disorder

Dr. Eggerding called for a motion. Ms. Bell moved and seconded by Dr. Evans to accept the recommendation to fund CAUT17BSP022.

3. Following a brief discussion, the MOTION to approve the recommendation to fund CAUT17BSP022 was passed with seven members in favor and two abstaining.

CAUT17BSP024

Characterization of the female phenotype of ASD using Big Data

Dr. Eggerding called for a motion. Mr. Weitzen moved and seconded by Dr. Aquino to accept the recommendation to fund CAUT17BSP024 with the condition to fund only Aim #1.

4. Following a brief discussion, the MOTION to approve the recommendation to fund Aim #1, CAUT17BSP024 was passed with seven members in favor and two abstaining.

CAUT17BSP010

Immune Regulation of Neural Stem/Progenitors

Dr. Eggerding called for a motion. Ms. Bell moved and seconded by Dr. Evans to accept the recommendation to fund CAUT17BSP010.

5. Following a brief discussion, the MOTION to approve the recommendation to fund CAUT17BSP010 was passed with seven members in favor and two abstaining.

CAUT17BSP021

White matter, myelination and the role of CASPR2 in autism

Dr. Eggerding called for a motion. Mr. Weitzen moved and seconded by Dr. Evans to accept the recommendation not to fund CAUT17BSP021.

6. MOTION to approve the recommendation not to fund CAUT17BSP021 was passed with seven members in favor and two abstaining.

CAUT17BSP012

Beneficial effects of early intervention on social reciprocity in an animal model of autistic regression

Dr. Eggerding called for a motion. Ms. Bell moved and seconded by Dr. Wang to accept the recommendation not to fund CAUT17BSP012.

7. MOTION to approve the recommendation not to fund CAUT17BSP012 was passed with seven members in favor and two abstaining.

CAUT17BSP020

Neural basis of selective visual processing in ASD and neurotypical development

Dr. Eggerding called for a motion. Mr. Weitzen moved and seconded by Dr. Evans to accept the recommendation not to fund CAUT17BSP020.

8. MOTION to approve the recommendation not to fund CAUT17BSP020 was passed with eight members in favor and one abstaining.

CAUT17BSP006

Role of Cypin in Forebrain Development and Neurobehavior Relevant to Autism

Dr. Eggerding called for a motion. Dr. Evans moved and seconded by Mr. Weitzen to accept the recommendation not to fund CAUT17BSP006.

9. MOTION to approve the recommendation not to fund CAUT17BSP006 was passed with seven members in favor and two abstaining.

CAUT17BSP016

Understanding abnormal cortical circuitry and the role of the ribosome signature in the neocortical development of a co-morbid autism and epilepsy mouse model

Dr. Eggerding called for a motion. Dr. Evans moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT17BSP016.

10. MOTION to approve the recommendation not to fund CAUT17BSP016 was passed with seven members in favor and two abstaining.

CAUT17BSP014

Genetic and behavioral analysis of endogenous opioid systems and autism

Dr. Eggerding called for a motion. Dr. Aquino moved and seconded by Mr. Weitzen to accept the recommendation not to fund CAUT17BSP014.

11. MOTION to approve the recommendation not to fund CAUT17BSP014 was passed with seven members in favor and two abstaining.

CAUT17BSP019

Repairing MeCP2 mutations in Rett's syndrome patients using a multifunctional nanoparticlebased CRISPR/Cas9 method

Dr. Eggerding called for a motion. Ms. Bell moved and seconded by Dr. Wang to accept the recommendation not to fund CAUT17BSP019.

12. MOTION to approve the recommendation not to fund CAUT17BSP019 was passed with seven members in favor and two abstaining.

CAUT17BSP002

Zebrafish: an alternative model for the study of Rett syndrome

Dr. Eggerding called for a motion. Dr. Friedman moved and seconded by Dr. Wang to accept the recommendation not to fund CAUT17BSP002.

13. MOTION to approve the recommendation not to fund CAUT17BSP002 was passed with all members in favor.

CAUT17BSP027

Identifying and testing novel treatments in the fly and mouse models of Fragile X syndrome

Dr. Eggerding called for a motion. Dr. Dreyfus moved and seconded by Dr. Friedman to accept the recommendation not to fund CAUT17BSP027.

14. MOTION to approve the recommendation not to fund CAUT17BSP027 was passed with all voting members in favor.

CAUT17BSP007

The mTOR pathway controls cerebral oxygen consumption in a model of autism-tuberous sclerosis

Dr. Eggerding called for a motion. Ms. Bell moved and seconded by Dr. Evans to accept the recommendation not to fund CAUT17BSP007.

15. MOTION to approve the recommendation not to fund CAUT17BSP007 was passed with seven members in favor and two abstaining.

CAUT17BSP008

INVESTIGATING REGULATORY MECHANISMS IN AUTISM SPECTRUM DISORDER

Dr. Eggerding called for a motion. Ms. Bell moved and seconded by Dr. Friedman to accept the recommendation not to fund CAUT17BSP008.

16. MOTION to approve the recommendation not to fund CAUT17BSP008 was passed with all voting members in favor.

The following grant applications were triaged:

CAUT17BSP004 Endocannabinoid System Alterations in Autism Spectrum Disorders (ASDs) CAUT17BSP005 Activity-dependent processes in mouse social behavior

CAUT17BSP009 Understanding the extracellular matrix regulation in cognitive profile of Neurofibromatosis 1 as a therapeutic tool CAUT17BSP015 Experience-dependent dendritic spine structural plasticity in ASD

CAUT17BSP018 Assessment of biophysical rhythms in neonates for early identification of risk for stunted neuro-motor development

CAUT17BSP028 Identifying and testing the efficacy of novel treatments in autism models

Clinical Research Pilot Grant Applications

CAUT17APL013

Characterizing the Trajectory of Autism Spectrum Disorder (ASD) in Adolescents

Dr. Eggerding called for a motion. Dr. Evans moved and seconded by Mr. Macchiaverna to accept the recommendation to fund CAUT17APL013.

17. Following a brief discussion, the MOTION to approve the recommendation to fund CAUT17APL013 was passed with seven members in favor and two abstaining.

CAUT17APL025

A Pilot/Feasibility Study of the Use of High Dose Propranolol to Treat Severe and Chronic Challenging Behaviors in Adolescents and Adults with Autism Spectrum Disorders

Dr. Eggerding called for a motion. Mr. Macchiaverna moved and seconded by Mr. Weitzen to accept the recommendation to fund CAUT17APL025

18. Following a brief discussion, the MOTION to approve the recommendation to fund CAUT17APL025 was passed with seven members in favor and two abstaining.

CAUT17APL009

Identifying Genetic and Behavioral Correlates of Sensory Issues in Autism Spectrum
Disorders

Dr. Eggerding called for a motion. Dr. Wang moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT17APL009.

19. Following a brief discussion, the MOTION to approve the recommendation not to fund CAUT17APL009 was passed with seven members in favor and two abstaining.

CAUT17APL003

Elucidating Genetics of Autism and Co-occurring Conditions using Whole Genome Sequence

Dr. Eggerding called for a motion. Dr. Evans moved and seconded by Mr. Weitzen to accept the recommendation not to fund CAUT17APL003.

20. Following a brief discussion, the MOTION to approve the recommendation not to fund CAUT17APL003 was passed with seven members in favor and two abstaining.

CAUT17APL030

Microbiome-Immune Disturbances in Autism

Dr. Eggerding called for a motion. Dr. Aquino moved and seconded by Mr. Weitzen to accept the recommendation to not fund CAUT17APL030.

21. Following a brief discussion, the MOTION to approve the recommendation not to fund CAUT17APL030 was passed with seven members in favor and two abstaining.

CAUT17APL011

Investigation of Multiple Air Toxics as a Risk Factor for Autism Spectrum Disorder

Dr. Eggerding called for a motion. Ms. Bell moved and seconded by Mr. Weitzen to accept the recommendation to not fund CAUT17APL011.

22. MOTION to approve the recommendation not to fund CAUT17APL011 was passed with seven members in favor and two abstaining.

CAUT17APL023

Neuronal abnormalities in Tuberous Sclerosis Complex, a genetic disease related to autism

Dr. Eggerding called for a motion. Mr. Weitzen moved and seconded by Dr. Wang to accept the recommendation to not fund CAUT17APL023.

23. MOTION to approve the recommendation not to fund CAUT17APL023 was passed with seven members in favor and two abstaining.

CAUT17APL037

Barriers to Positive Employment Outcomes for Adults with ASD

Dr. Eggerding called for a motion. Mr. Weitzen moved and seconded by Dr. Wang to accept the recommendation to not fund CAUT17APL037.

24. MOTION to approve the recommendation not to fund CAUT17APL037 was passed with seven members in favor and two abstaining.

CAUT17APL033

A Randomized Placebo-Controlled Study of Metformin Safety and Effects on Cognition, Anxiety and Sleep in Fragile X syndrome

Dr. Eggerding called for a motion. Dr. Friedman moved and seconded by Dr. Dreyfus to accept the recommendation not to fund CAUT17APL033.

25. MOTION to approve the recommendation not to fund CAUT17APL033 was passed with all voting members in favor.

CAUT17APL019

Sleep problems in children with autism

Dr. Eggerding called for a motion. Ms. Bell moved and seconded by Dr. Evans to accept the recommendation not to fund CAUT17APL019.

26. MOTION to approve the recommendation not to fund CAUT17APL019 was passed with seven members in favor and two abstaining.

CAUT17APL029

Investigating phenotypic overlap between autism and another language disorder, Specific Language Impairment (SLI).

Dr. Eggerding called for a motion. Dr. Aquino moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT17APL029.

27. MOTION to approve the recommendation not to fund CAUT17APL29 was passed with seven members in favor and two abstaining.

CAUT17APL016

THE GUT AND AUTISM: A METABOLONIC STUDY

Dr. Eggerding called for a motion. Dr. Dreyfus moved and seconded by Dr. Friedman to accept the recommendation not to fund CAUT17APL016.

28. MOTION to approve the recommendation not to fund CAUT17APL016 was passed with all members in favor.

CAUT17APL024

Relationships of human neural stem cell phenotypes to sensory-motor functions in idiopathic autism

Dr. Eggerding called for a motion. Dr. Wang moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT16APL024.

29. MOTION to approve the recommendation not to fund CAUT17APL024 was passed with seven members in favor and two abstaining.

CAUT17APL026

Towards Mobile Health in Autism Spectrum Disorder (ASD): Wearable-based outcome measures of transfer and generalization of functional gains from the clinic to the home

Dr. Eggerding called for a motion. Dr. Wang moved and seconded by Dr. Evans to accept the recommendation not to fund CAUT17APL026.

30. MOTION to approve the recommendation not to fund CAUT17APL026 was passed with seven members in favor and two abstaining.

CAUT17APL020

An Evaluation of the Effectiveness of Autism-Specific Traffic Warning Signs

Dr. Eggerding called for a motion. Dr. Wang moved and seconded by Dr. Evans to accept the recommendation not to fund CAUT17APL020.

31. MOTION to approve the recommendation not to fund CAUT17APL020 was passed with seven members in favor and two abstaining.

The following grant applications were triaged:

CAUT17APL008 Improving access to ASD diagnosis through telemedicine

CAUT17APL018 Generalization of a successful treatment trial with sulforaphane in autism in a NJ population: extension to other age groups, DSM-5 criteria of autism spectrum disorder and in female subjects with autism

CAUT17APL028 Patient-specific Repairing L1 syndrome mutant gene using Non-viral CRISPR/Cas9 system combined Homologous Stem Cell Therapy

CAUT17APL031 Evaluation of the Relationship between Autism Spectral Disorders (ASD) and Sudden Infant Death Syndrome (SIDS)

Medical Homes Grant Applications

CAUT17MED005

Autism Care Coordination Youth Program (ACCYP)

Dr. Eggerding called for a motion. Dr. Friedman moved and seconded by Dr. Dreyfus to accept the recommendation to fund CAUT17MED005. There was a discussion concerning the deliverables required by the grant and the lack of involvement of medical providers serving adults with autism.

32. MOTION to approve the recommendation to fund CAUT17MED005, emphasizing the need to include medical providers serving adults with autism, was passed with all members in favor.

CAUT17MED001

Autism Health Needs Home at Saint Peter's University Hospital

Dr. Eggerding called for a motion. Dr. Friedman moved and seconded by Dr. Dreyfus to accept the recommendation not to fund CAUT17MED001.

33. MOTION to approve the recommendation not to fund CAUT17MED001 was passed with all members in favor.

CAUT17MED002

Care 2 Share – Creation of a Medical Home for Adolescents and Young Adults on the Autism Spectrum at Rutgers- New Jersey Medical School in Newark

Dr. Eggerding called for a motion. Ms. Bell moved and seconded by Mr. Weitzen to accept the recommendation not to fund CAUT17MED002.

34. MOTION to approve the recommendation not to fund CAUT17MED002 was passed with seven members in favor and two abstaining.

V. NJACE Coordinating Center Report

Ms. Karen Hood-Kasim, Program Coordinator and Dr. Eileen McKeating, Research Associate reported on the activities of the Coordinating Center including their work with the NJACE grantees and provided an update on the 2017 Summit. They encouraged Council members to attend the Summit indicating they would resend the invitation and registration information to members.

VI. Report of the Acting Executive Director: Dr. Zanna thanked Ms. Hood-Kasim and Dr. McKeating for their reports on the work of the Coordinating Center.

<u>Ethics Requirements:</u> Four members have not fulfilled the ethics requirements. Linda Boclair will resend links to the information, upon request.

<u>Council's Webpage:</u> The Council's web-page is re-designed in keeping with the re-design of all DOH web sites with the intent of standardizing the look and accessibility to information. <u>Comments from two members of the Scientific Advisory Committee (SAC):</u> We were pleased with the feedback from Drs. Susan Hyman and Catherine Rice, both SAC members,

concerning the work of the Council. Linda Boclair sent the letter from Dr. Hyman and comments from Dr. Rice to Council members.

<u>SFY'17 RFA:</u> We are almost at the end of the SFY'17 grant cycle with awards for the grants approved tonight to be officially awarded by June. Dr. Zanna thanked members for the time they invested in developing the RFA and in reviewing the grant applications, critiques and notes from the review panels.

<u>Council's 2016 Annual Report</u>: Although Dr. Zanna announced copies of the Council's 2016 Annual Report were distributed at the meeting it was later discovered information had been deleted during formatting and would have to be reprinted. Members were notified via email to discard the reports with corrected reports to be mailed as soon as possible.

<u>Rutgers University:</u> Work with Rachel Hammond, DOH Ethics Officer, continues with the request to permit Council members who are employees of Rutgers to vote on grant applications and grants from Rutgers if the grant applications/grants are not from or connected to the Council member's home campus. The request will be discussed at the State Ethics Commission (SEC) on April 12, 2017. Note: the discussion was later postponed to the SEC May 16, 2017 meeting.

Management of Revenue from Motor Vehicle Violations: As the result of a request from Dr. Aquino, there will be a discussion at the June 5 Council meeting regarding the Autism Medical Research and Treatment Fund, specifically how and when revenues are deposited into the Fund and when the money is appropriated with the goal of strategizing on how to better manage the incoming money to make sure funds are used as intended.

VIII. Report of Revenues and Expenditures

Copies of the Report of Revenues and Expenditures were sent to Council members for their information.

IX. Election of the Council Chair

Dr. Evans nominated Dr. Eggerding. There were no additional nominations. Ballots were distributed; members voted and elected Dr. Eggerding as Chairperson for 2017. Dr. Zanna congratulated Dr. Eggerding as she continues to chair the Council. Dr. Eggerding thanked the members.

X. Adjournment

Dr. Eggerding asked for a motion to adjourn.

35. MOTION to adjourn by Dr. Evans and seconded by Dr. Dreyfus was approved with all members in favor. The meeting was adjourned at 9:00 PM.